



End of Life Care October 2003

1: Am J Geriatr Psychiatry. 2003 May-Jun;11(3):309-19.

The Stressful Caregiving Adult Reactions to Experiences of Dying (SCARED) Scale: a measure for assessing caregiver exposure to distress in terminal care.

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OBJECTIVE: The authors evaluated the performance of the Stressful Caregiving Adult Reactions to Experiences of Dying (SCARED) scale, a new tool to assess caregiver exposure to patient distress, and the fear and helplessness evoked by these experiences. **METHODS:** The SCARED was administered to 76 hospice-patient caregivers (e.g., family members). Major depressive disorder (MDD) was diagnosed with the Structured Clinical Interview for the DSM-IV; complicated grief (CG) "caseness" was diagnosed with the Inventory of Complicated Grief-Caregiver items, and quality-of-life domains were assessed with the Medical Outcomes Survey Short Form-36. **RESULTS:** Respondents endorsed frequent exposure to each SCARED experience-from 30.3% who mistakenly thought the patient had died, to 80.3% who witnessed the patient in severe pain. Adjusted analyses revealed that the odds of MDD increased by 3.08 for each standard-deviation increase in the SCARED event frequency score and that higher SCARED scores were positively associated ($p < 0.05$) with social and role impairment, less energy, and more negative health perceptions. **CONCLUSION:** The SCARED may be a clinically useful tool for identifying caregivers at risk for MDD and quality-of-life impairments, as well as potential aspects of caregiving to target for treatment.

PMID: 12724110 [PubMed - indexed for MEDLINE]

2: Am J Health Syst Pharm. 2003 Jun 15;60(12):1246-50.

Content on end-of-life care in major pharmacy textbooks.

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The quantity and quality of end-of-life-care (EOLC) information in commonly used pharmacy textbooks were studied. EOLC content in each of eight best-selling pharmacy textbooks was assigned to 1 of 13 domains; there were a total of 104 possible domains for all eight books. Every mention of EOLC was given a score of 2 for "helpful content present" or 1 for "minimal content present." The quantity of EOLC content was assessed by tabulating the raw number of entries. The average number of EOLC-related entries per book ranged from 1.0 (ethics) to 27.5 (natural history). Eighty-one domains (78%) had fewer than 10 entries, 66 (63%) had 5 or fewer entries, and 28 (27%) had 1 entry or none. The overall quality of content was low, especially in the domains of spiritual issues, ethics, and context of care. The results were consistent with findings for medicine and nursing textbooks. A review of eight commonly used pharmacy textbooks revealed inadequate coverage of EOLC.

Publication Types:
Evaluation Studies

PMID: 12845920 [PubMed - indexed for MEDLINE]

3: Am J Hosp Palliat Care. 2003 Sep-Oct;20(5):340-4.

End-of-life care education in United States pharmacy schools.

Herndon CM, Jackson K 2nd, Fike DS, Woods T.

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Hospice and palliative care have undergone dramatic changes in the past 30 years. Educational initiatives and certification programs for physicians (American Board of Hospice and Palliative Medicine) and nurses (National Board for Certification of Hospice and Palliative Nurses) have further delineated this area of practice as distinct from geriatrics, neurology, anesthesiology, or oncology. As other professions assess their own practices of hospice and end-of-life (EOL) care education in their respective schools and colleges, the pharmacy profession must also ensure that its future graduates are prepared to adequately participate in this type of care. This was a descriptive study in which all accredited schools and colleges of pharmacy in the US were queried regarding their level of curricular commitment to EOL care. Eighty-three questionnaires were mailed, and 60 schools responded (72 percent). Four primary informational items regarding EOL and palliative care education were targeted, including availability of didactic teaching, specialization of pharmacy faculty, availability and type of clerkships, and method of instruction. Sixty-two percent of respondents indicated EOL care education was provided didactically (3.89 +/- 1.91 lecture hours per year). Fifty-eight percent of respondents indicated that EOL care experiential clerkships were available (4.97 +/- 1.25 weeks in duration). These data indicate that over half of US pharmacy students receive some exposure to EOL care education.

PMID: 14529036 [PubMed - in process]

4: Am J Hosp Palliat Care. 2003 Sep-Oct;20(5):360-70.

Satisfaction of families using end-of-life care: current successes and challenges in the hospice industry.

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This study examined the satisfaction of family members with the end-of-life care their loved ones received. Data were collected from 1,839 individuals receiving care from 17 different care agencies nationwide. Although family satisfaction with hospice care was generally quite high, situational factors played a role. The timing of the referral was critical, with families rating services lower almost across the board when the referral to hospice was deemed "too late." Additionally, families expressed greater satisfaction when the patient's care was overseen by the hospice director, rather than a personal physician. Each of these findings has important implications for physicians, patients, and families as they begin to plan for end-of-life care.

PMID: 14529039 [PubMed - in process]

5: Am J Hosp Palliat Care. 2003 Sep-Oct;20(5):371-81.

An analysis of provider attitudes toward end-of-life decision-making.

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The explosion of technological and biomedical interventions over the past half century appears to have enhanced the medical profession's ability to prolong life at a faster pace than society's ability to develop comprehensive bioethical laws governing end-of-life decisions. This study was conducted to determine if there was a correlation between educational and occupational backgrounds and participants' perceptions of end-of-life care. Study participants came from various areas and levels of healthcare at a large federal healthcare facility and included nurses, doctors, pharmacists, dietitians, administrators, and others. Participants completed a questionnaire providing both sociodemographic information and perceptions of end-of-life care. Respondents were classified by type of education or background (technical, professional, or medical) and by level of involvement with patient care (direct or indirect). While the results showed a general consensus about the importance of respecting patients' end-of-life wishes, there were differences among respondents in regard to specific issues.

PMID: 14529040 [PubMed - in process]

6: Am J Hosp Palliat Care. 2003 Jul-Aug;20(4):269-73.

Dying to meet you: facing mortality and enabling patient styles.

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This paper is intended to emphasize the existence of prognostic uncertainty in providing survival estimates while also providing a method for caring to those who want to authentically help dying patients. Facing one's own mortality helps one compassionately be there for dying patients. The transforming experience of death as essential to one's self as human being, recognizing that one is living a story with death necessarily a part, promises to overcome the tendency to deny the existential meaning of death for dying patients. This tendency manifests itself through dishonesty about medicine's limitations in creating prognoses, and specifically survival estimates, as well as in holding only a curative and not palliative goal of treatment. This tendency will be replaced by honest and compassionate actions with those in the process of dying. Representing this change is a focus on the patient as person, living a certain lifestyle, and defining himself by significant events and relationships in the past, present, and future. Death and dying become meaningful through incorporation into the story and style that is the patient. This meaning that is facilitated by caregivers and created by patients is central to achieving a "good death."

Publication Types:

Review

Review, Tutorial

PMID: 12911071 [PubMed - indexed for MEDLINE]

7: Am J Hosp Palliat Care. 2003 Jul-Aug;20(4):279-89.

A syllabus for fellowship education in palliative medicine.

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Recent years have seen significant growth in palliative medicine training programs and positions. There are plans to pursue palliative medicine specialty status with the American Board of Medical Specialties and accreditation of fellowship programs with the American College of Graduate Medical Education. A work group of program directors, supported initially by the Cleveland Clinic and then by the American Board of Hospice and Palliative Medicine, has recently published standards for fellowship training. Despite this, fundamental questions remain about defining the field and delineating the knowledge and skills expected following completion of specialty training. In this article, we describe the first fellowship program in palliative medicine (PMP) in the United States, developed and supported by the Cleveland Clinic Foundation. The program has been implemented as part of the Harry R. Horvitz Center for Palliative

Medicine, founded in 1987 as the first comprehensive integrated US program in this field. This training program, in existence since 1989, features a traditional rotational structure with an inpatient primary care service, inpatient consult services, and an outpatient consult/hospice service. This article outlines the syllabus developed for this fellowship, given what we believe to be the essential knowledge base for the field of palliative medicine.

PMID: 12911073 [PubMed - indexed for MEDLINE]

8: Am J Hosp Palliat Care. 2003 Jul-Aug;20(4):290-6.

Hospice care in prison: general principles and outcomes.

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In recent years, tougher sentencing laws have resulted in larger numbers of elder prison inmates and, consequently, more deaths occurring in prisons. In this context, the introduction of prison hospice programs takes on great significance. The purpose of this study is to identify the principle components and outcomes of prison hospice programs based on data gathered from semistructured telephone interviews with prison hospice providers in state and federal correctional institutions and from other sources. The results suggest that there is a growing effort to provide palliative care to dying inmates across the country and that all of the existing programs share common elements and similar structures. Major outcomes of prison hospice programs include cost-effectiveness, enhanced correction, and comfort care.

PMID: 12911074 [PubMed - indexed for MEDLINE]

9: Am J Hosp Palliat Care. 2003 Jul-Aug;20(4):263-8.

A systematic review on chaplains and community-based clergy in three palliative care journals: 1990-1999.

Flannelly KJ, Weaver AJ, Smith WJ, Oppenheimer JE.

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A systematic review of all articles appearing between 1990 and 1999 in the American Journal of Hospice and Palliative Care, the Hospice Journal, and the Journal of Palliative Care was conducted. Articles citing at least one reference were categorized as scholarly, included in the study, and divided into either research or nonresearch categories. Scholarly articles were classified as research if they contained clearly defined methods and results sections, even if these headings were not used. Research and nonresearch articles were subdivided into qualitative and quantitative research and general reviews or program descriptions, respectively. All scholarly articles were read to see if they mentioned clergy, including the terms rabbi, priest, minister, pastor, imam,

chaplain, or other religious professionals. Of 838 scholarly articles published between 1990 and 1999 in the three journals, 348 (41.5 percent) were research articles, 417 (49.8 percent) were reviews, and 73 (8.7 percent) were program descriptions. Forty-seven (5.6 percent) of all 838 scholarly articles mentioned clergy or chaplains in some way. Clergy and chaplains were more likely to be an integral part of research articles, whereas mention of them in nonresearch articles tended to be incidental (chi-square = 16.8, $p < .001$). Moreover, quantitative articles were more likely to include clergy as an integral aspect of the article than were qualitative articles (Fischer's exact probability test, $p = .088$). The results are discussed with respect to the mutual roles hospice chaplains and community-based clergy play in providing spiritual care at the end of life.

Publication Types:

Review

Review, Academic

PMID: 12911070 [PubMed - indexed for MEDLINE]

10: Am J Hosp Palliat Care. 2003 Jul-Aug;20(4):259-61.

Obstacles to the delivery of acceptable standards of care in rural home hospices.

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PMID: 12911068 [PubMed - indexed for MEDLINE]

11: Am J Kidney Dis. 2003 Oct;42(4):813-20.

The need for end-of-life care training in nephrology: National survey results of nephrology fellows.

Holley JL, Carmody SS, Moss AH, Sullivan AM, Cohen LM, Block SD, Arnold RM.

Because of the high mortality rate of end-stage renal disease, nephrologists care for many dying patients. However, the education of nephrology fellows in palliative care has not been assessed. We surveyed second-year nephrology fellows to assess the quantity and quality of teaching they received in palliative medicine and also asked about their preparedness to manage patients at the end of life. A 63% survey response rate yielded 173 surveys for evaluation. Nearly all fellows (99%) agreed that physicians have a responsibility to help patients at the end of life; half thought it was very important to learn how to care for dying patients. On a 10-point scale in which 0 is no teaching and 10 is a lot of teaching, fellows reported significantly less teaching in end-of-life care (mean score, 3.8 +/- 2.6) than in managing a patient with distal renal tubular acidosis (mean score, 6.3 +/- 2.5) or on hemodialysis therapy (mean score, 8.9 +/- 1.5; all $P < 0.0001$). Specific palliative care content areas were taught infrequently; only 22% of fellows were

taught how to tell a patient he or she is dying. Fellows who had contact with a palliative care specialist reported more education on end-of-life issues and believed they were better prepared to provide such care. Fellows' palliative care experiences during fellowship frequently occurred without attending nephrologist supervision; 32% of fellows had conducted 2 or fewer family meetings, and 26% of all family meetings occurred without an attending nephrologist. Fellows believed they were best prepared to manage a patient on hemodialysis therapy (mean score, 8.9 +/- 1) and least prepared to manage a patient at the end of life (mean score, 6.1 +/- 2; $P < 0.0001$). Our results show that most nephrology fellows believe they should learn how to care for dying patients, but most fellowship programs do not offer this training. Our study therefore suggests that training in palliative care be incorporated into fellowship program curricula.

PMID: 14520633 [PubMed - in process]

12: Am J Nurs. 2003 Sep;103(9):47.

Mercy in the room. Interview by Sylvia Foley.

Levine S.

Publication Types:
Interview

PMID: 14506806 [PubMed - indexed for MEDLINE]

13: Am J Nurs. 2003 Sep;103(9):42-6, 48-52; quiz 53.

Grief and bereavement care.

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PMID: 14501473 [PubMed - indexed for MEDLINE]

14: Ann Intern Med. 2003 Sep 2;139(5 Pt 2):410-5.

Measuring and improving the quality of dying and death.

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Improving end-of-life experience is a major challenge to successful aging. Deaths that are reasonably free of discomfort, in accordance with patients' wishes, and within acceptable professional and ethical standards are

high-quality deaths. The authors developed a 31-item measure of the quality of dying and death and applied it in a community sample and a sample of hospice enrollees. Scores on the Quality of Dying and Death Instrument and measures of perceived quality of care were collected from patients' loved ones after death. Higher overall after-death ratings of the quality of care received from all providers and from physicians were associated with higher-quality dying and death. How well patients' symptoms were controlled in the community study and how well wishes were followed and treatments were explained in the hospice study were associated with higher-quality dying. Major challenges to end-of-life research include recruiting representative population samples, given widespread reluctance of patients and loved ones to participate in research at the end of life; important variation in evaluations among different reporters after death; reluctance of loved ones to assign negative evaluations to dying experiences after death; and the highly individual and dynamic nature of dying experiences. Overcoming these challenges is of great importance in the search for the social, organizational, and individual determinants of high-quality dying in the U.S. cultural and health care context.

Publication Types:

Review

Review Literature

PMID: 12965967 [PubMed - indexed for MEDLINE]

15: Ann R Coll Physicians Surg Can. 2001 Oct;34(7):441-3.

In long-term care, the "R" in CPR is not for resurrection.

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Objective: To determine whether the concept of the "R" in CPR (cardiopulmonary resuscitation) not meaning resurrection as opposed to resuscitation is a useful explanation to families of patients in long-term care why CPR may not be recommended. Methods: A review of the relevant literature and such ideas as futility was used to develop the conceptual basis for the discussion.

Conclusion: There is enough evidence to support the position that for the frail, elderly, long-term care patient, the concept of resurrection rather than resuscitation can be a useful explanation to families why CPR should not be attempted in most circumstances.

PMID: 12962084 [PubMed - indexed for MEDLINE]

16: Aust Crit Care. 2003 Aug;16(3):84-5.

Improving end-of-life care in the intensive care unit: are nurses involved?

Latour JM.

Publication Types:
Editorial

PMID: 14533210 [PubMed - in process]

17: Best Pract Res Clin Anaesthesiol. 2003 Jun;17(2):273-87.

The ethics of end-of-life decisions in the elderly: deliberations from the ECOPE study.

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Is age a factor underlying clinical decision-making? Should age be a criterion in the allocation of health care resources? Is it correct to criticize this approach as 'ageism'? What role does 'paternalism' play? These questions are the focus of this chapter which takes an interdisciplinary perspective of clinical ethics in order to provide an ethical evaluation of the situation of the elderly in health care. First, the text of the chapter is based on the descriptive level referring to (a) clinical ethics consultation, (b) the ECOPE study on 'Ethical Conditions of Passive Euthanasia' focusing on decision-making, and studies about age as a factor in clinical decisions, such as the American SUPPORT study. Second, at the normative level, ethical deliberations are discussed for and against age as a criterion for allocating health care resources. Finally, it is suggested that the differences in evidence to be found about the role of age as a factor in clinical decision-making may be due to the different national health policies as well as to the insufficient awareness of ethical principles violated by covert 'ageist' attitudes.

Publication Types:
Review
Review, Tutorial

PMID: 12817920 [PubMed - indexed for MEDLINE]

18: BMJ. 2003 Sep 13;327(7415):595-6.

Doctors' opinions on euthanasia, end of life care, and doctor-patient communication: telephone survey in France.

Peretti-Watel P, Bendiane MK, Pegliasco H, Lapiana JM, Favre R, Galinier A, Moatti JP.

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PMID: 12969926 [PubMed - indexed for MEDLINE]

19: BMJ. 2003 Sep 13;327(7415):614-5.

Doctors should not discuss resuscitation with terminally ill patients: FOR.

Manisty C, Waxman J.

Department of Cancer Medicine, Faculty of Medicine, Imperial College of Science, Technology and Medicine, Hammersmith Campus, London W12 0NN.

PMID: 12969934 [PubMed - indexed for MEDLINE]

20: Br J Cancer. 2003 Aug;89 Suppl 1:S107-10.

Summary version of the Standards, Options and Recommendations for palliative or terminal nutrition in adults with progressive cancer (2001).

Bachmann P, Marti-Massoud C, Blanc-Vincent MP, Desport JC, Colomb V, Dieu L, Kere D, Melchior JC, Nitenberg G, Raynard B, Roux-Bournay P, Schneider S, Senesse P; FNCLCC.

Centre Leon Berard, Lyon, France.

Publication Types:

Guideline

Practice Guideline

PMID: 12915911 [PubMed - indexed for MEDLINE]

21: Can J Anaesth. 2003 Oct;50(8):847-52.

Futility-of-care decisions in the treatment of moribund intensive care patients in a developing country: [L'acharnement therapeutique pour des moribonds a l'unite des soins intensifs dans un pays en developpement].

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PURPOSE: To analyze the characteristics of moribund patients in a surgical intensive care unit (ICU) and highlight the dilemmas inherent in treating such patients. **METHODS:** Data on all patients admitted to the surgical ICU during the period of three years from July 1999 to June 2002 were collected prospectively. Data were collected on very ill patients who died, in whom it appeared obvious that treatment could not have improved their condition and whose death could have been anticipated. The case notes were subjected to further analysis to determine the difficulties encountered in managing patients whose therapy was considered to be futile. **RESULTS:** Of 662 admissions, 100 (15.1%) died and 30 (4.5%) patients were treated aggressively, even after a prognosis which reflected futile treatment. The overall mean length of stay for survivors was

7.5 +/- 9.0 [standard deviation (SD)] days and that for the non-survivors was 12.8 +/- 18.1 (SD; P < 0.001). The cost incurred for the treatment of non-survivors was significantly higher than that for the surviving patients. The factors relating to the decisions to continue futile therapy were age of the patient, legal considerations, family wishes and differing opinions between treating physicians. CONCLUSION: Consideration of futility during end-of-life care did not receive adequate attention in this unit which incurred additional human and material resources.

PMID: 14525828 [PubMed - in process]

22: Cancer Nurs. 2003 Aug;26(4):267-75.

Family experience caring for terminally ill patients with cancer in Hong Kong.

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In this study, 24 family caregivers of terminally ill patients participated in in-depth interviews regarding their experiences of giving care. The data were analyzed using grounded theory qualitative method. Commitment emerged as the precondition of the caregiving process. The caregivers did not perceive the work of caring as a burden. Rather, they felt that despite any personal hardships, what they were doing was important to their loved ones and therefore meaningful to them as caregivers. The components of commitment can be described as relational commitment, the act of showing love, and determination. The process of caregiving includes four phases: 1) holding onto hope for a miracle, 2) taking care, 3) preparing for death, and 4) adjusting to another phase of life. A patient-caregiver relationship, Confucian concepts of yi (appropriateness or rightness), and filial duty are reflected in the process of caregiving. Consequences of the process include finding meaning in life and peace of heart and mind. The emotional aspect of the caregiving experience can be described as an intense emotional experience filled with feelings of hope and hopelessness, guilt, fear, and regret. As a result of the caregiving experience, most participants found they have had a change of worldviews and treasure their lives. Findings show a significant need for interventions at each phase of the caregiving process designed to provide effective and culturally sensitive support and affirmation to family members as they care for their loved ones with terminal illnesses.

PMID: 12886117 [PubMed - indexed for MEDLINE]

23: Cancer Nurs. 2003 Aug;26(4):276-83.

The difficulties faced by informal caregivers of patients with terminal cancer in Hong Kong and the available social support.

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This study aimed to explore the difficulties experienced by primary informal caregivers of Chinese patients with terminal cancer in Hong Kong and the social support available for such caregivers. For this exploratory study, 21 primary informal caregivers of patients with terminal cancer were recruited from a hospice home service to complete a questionnaire. The results show that all but one of the caregivers (95.2%) perceived difficulties in rendering care. They reported experiencing four major kinds of difficulties: relationship with the care receiver (n = 11, 52.4%), emotional reactions to caring (n = 9, 42.9%), physical demands (n = 10, 47.6%), and restricted social life (n = 11, 52.4%). Of the 21 caregivers, 20 (95.2%) felt that the support received from hospice home care nurses was useful, especially in skill training (n = 16, 76.2%), informational support (n = 20, 95.2%), and emotional support (n = 20, 95.2%). Informal caregivers also indicated that home care nurses provided more useful overall support than family members and friends (chi² = 11.35; P = .003). With a better understanding of the difficulties experienced by caregivers and the support they receive, hospice home care nurses will be in a better position to identify effective strategies for helping informal caregivers cope with their difficult circumstances.

PMID: 12886118 [PubMed - indexed for MEDLINE]

24: Caring. 2003 Jul;22(7):42-4.

CMS panel responds to hospice survey and certification questions.

[No authors listed]

PMID: 12959037 [PubMed - indexed for MEDLINE]

25: Case Manager. 2003 Jul-Aug;14(4):47-9.

Are viatical settlements appropriate for your patients?

Petrie D.

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PMID: 12869948 [PubMed - indexed for MEDLINE]

26: Clin Med. 2003 May-Jun;3(3):232-4.

Ethical issues in ageing.

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Population ageing, in both the developed and developing world, has put increasing demands on health resources; this has brought to the fore various ethical issues related to ageing. This paper examines moral issues that confront people as they grow old as well as those who are involved with them. The concepts of autonomy, dignity, justice and intergenerational solidarity are explored. Living wills and the role of a proxy could help to deal with the common ethical dilemmas related to death and dying. Positive action by governments to overcome ageism is recommended. The need to establish ethical guidelines, which take into consideration differences in religion, culture, ethnicity and race, is highlighted.

PMID: 12848256 [PubMed - indexed for MEDLINE]

27: CMAJ. 2003 Aug 19;169(4):300-1.

New research initiatives in Canada for end-of-life and palliative care.

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PMID: 12925424 [PubMed - indexed for MEDLINE]

28: Crit Care Med. 2003 Sep;31(9):2255-62.

Quality indicators for end-of-life care in the intensive care unit.

Clarke EB, Curtis JR, Luce JM, Levy M, Danis M, Nelson J, Solomon MZ; Robert Wood Johnson Foundation Critical Care End-Of-Life Peer Workgroup Members.

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OBJECTIVE: The primary goal of this study was to address the documented deficiencies in end-of-life care (EOLC) in intensive care unit settings by identifying key EOLC domains and related quality indicators for use in the intensive care unit through a consensus process. A second goal was to propose specific clinician and organizational behaviors and interventions that might be used to improve these EOLC quality indicators. **PARTICIPANTS:** Participants were the 36 members of the Robert Wood Johnson Foundation (RWJF) Critical Care End-of-Life Peer Workgroup and 15 nurse-physician teams from 15 intensive care units affiliated with the work group members. Fourteen adult medical, surgical, and mixed intensive care units from 13 states and the District of Columbia in the United States and one mixed intensive care unit in Canada were represented. **METHODS:** An in-depth literature review was conducted to identify articles that assessed the domains of quality of EOLC in the intensive care unit and general health care. Consensus regarding the key EOLC domains in the intensive care unit and quality performance indicators within each domain was established based on the review of the literature and an iterative process involving the authors and

members of the RWJF Critical Care End-of-Life Peer Workgroup. Specific clinician and organizational behaviors and interventions to address the proposed EOLC quality indicators within the domains were identified through a collaborative process with the nurse-physician teams in 15 intensive care units. MEASUREMENTS AND MAIN RESULTS: Seven EOLC domains were identified for use in the intensive care unit: a) patient- and family-centered decision making; b) communication; c) continuity of care; d) emotional and practical support; e) symptom management and comfort care; f) spiritual support; and g) emotional and organizational support for intensive care unit clinicians. Fifty-three EOLC quality indicators within the seven domains were proposed. More than 100 examples of clinician and organizational behaviors and interventions that could address the EOLC quality indicators in the intensive care unit setting were identified. CONCLUSIONS: These EOLC domains and the associated quality indicators, developed through a consensus process, provide clinicians and researchers with a framework for understanding quality of EOLC in the intensive care unit. Once validated, these indicators might be used to improve the quality of EOLC by serving as the components of an internal or external audit evaluating EOLC continuous quality improvement efforts in intensive care unit settings.

PMID: 14501954 [PubMed - in process]

29: Dimens Crit Care Nurs. 2003 Sep-Oct;22(5):216-22.

Strategies to Improve End-of-life Care in the Intensive Care Unit.

Ciccarello GP.

SUMMARY: Death is a frequent occurrence in the intensive care unit (ICU). Critical care nurses often feel unprepared to deliver expert end-of-life care. This article proposes specific strategies for critical care nurses to improve the delivery of end-of-life care in the ICU. Critical care nurses can examine beliefs about death; recognize that cure and palliative care coexist; create an environment that supports dying as well as curing; improve communication among providers, patients, and families; provide "small things that make a big difference" at the end-of-life; and locate and utilize support for improving end-of-life care.

PMID: 14508248 [PubMed - in process]

30: Fam Med. 2003 Oct;35(9):637-42.

Unmet Need for Chronic Disease and End-of-Life Care at Urban Family Health Centers in the Bronx, NY.

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BACKGROUND AND OBJECTIVES: With population demographic shifts and as people live

longer with progressive incurable illnesses, there will be a growing need for community-based chronic disease and end-of-life care services. Family practice sites could be strategic community-based settings in which to offer chronic disease and end-of-life care. This study determined whether two urban family health centers were meeting the chronic disease and end-of-life care needs of health center users, their families, and the local community. METHODS: Using a brief structured interview instrument, we interviewed a convenience sample of 218 patients at two hospital-affiliated family health centers in the Bronx, NY, about their recent experiences with serious illness and death of immediate family members. In addition, we developed geographically defined medical service areas for each health center and compared the age distribution of residents of the geographic areas with that of actual health center users. RESULTS: Of 218 health center users, 18% (n=39) had experienced the death of an immediate family member in the past year, of whom only 8% (n=3) stated that their family member had received end-of-life/chronic disease care at the health center, and only 23% (n=9) knew that their family member could have received such care. Of 26% (n=56) of study subjects who reported having an immediate family member who was currently seriously ill, 18% (n=10) stated that their family members were receiving care at the health center, and 23% (n=13) knew that their family members could have received such care. Eighty percent (n=174) of study subjects stated that they themselves would be interested in receiving end-of-life/ chronic disease care at the health center in the event that they needed such care. The age distribution of health center users significantly differed from that of the residents of the geographically defined medical service areas, with an underrepresentation of people over the age of 75 among the health center users. CONCLUSIONS: We identified a potential unmet need for chronic disease and end-of-life care among families of health center users and the larger community served by two family health centers in the Bronx, NY. Despite the frequent occurrence of serious illness and recent death among close family members, relatively small proportions of these family members had received care at the health centers, and few actual users were aware that such services could be provided there. Moreover, there was a significant demographic mismatch in age distribution between health center users and the surrounding community. These findings signal an important opportunity for the discipline of family medicine and its training programs to define and respond to the chronic disease and end-of-life care needs of patients and their families in community-based settings.

PMID: 14523661 [PubMed - in process]

31: Fam Pract. 2003 Jun;20(3):304-10.

Organizing palliative care for rural populations: a systematic review of the evidence.

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BACKGROUND: Palliative care services have developed mostly in urban areas. Rural areas typically are characterized by the lack of well-organized services, with primary care professionals, specifically GPs and community nurses, having to

undertake most of the palliative care. Little is known, however, either of their views or of how best to organize palliative care in rural areas. OBJECTIVE: The aim of this study was to conduct a systematic literature review of studies that have examined the organization of rural palliative care and the views of professionals in rural areas. METHOD: Six electronic databases were searched for published studies between 1991 and 2001. Articles had to match against (i). MeSH or keyword terms relating to palliative, terminal or end of life care; and (ii). MeSH or keyword terms relating to rural. A data extraction framework was designed and used systematically by two reviewers to consider research question and method, sample characteristics, selection and size, study quality, summary results and implications. RESULTS: Twenty-six studies were identified. These were mostly questionnaire surveys and reports, and three qualitative studies. No randomized controlled studies or cohort studies were identified. Education and strategic issues were dominant research questions. Both the sample numbers and response rates in the surveys were variable. The qualitative studies had methodological strengths and elicited important views from nurses, carers and families. GPs were, however, unrepresented. Whilst the role of primary care emerged as an important theme, primary care professionals reported difficulties in obtaining education and training. There were also reported problems in symptom control and in the management of emotional issues such as bereavement counselling. Difficulties were also described in accessing specialist services such as hospices, and families were reported as having problems in accessing information. Developments in information technology such as telemedicine were seen as possible solutions to some of the problems. CONCLUSIONS: There is little published work on this topic. Most of the work identifies problems in the delivery of palliative care in rural areas. Whilst primary care professionals are seen as having a key role, there is a need to discover both their views and their needs in this field.

Publication Types:

Review

Review, Academic

PMID: 12738700 [PubMed - indexed for MEDLINE]

32: Hastings Cent Rep. 2003 May-Jun;33(3):9; discussion 9-10.

CPR in hospice.

Fine PG, Jennings B.

PMID: 12854449 [PubMed - indexed for MEDLINE]

33: Home Healthc Nurse. 2003 Jul;21(7):498.

HPNA educational resources for nursing assistants.

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PMID: 12905973 [PubMed - indexed for MEDLINE]

34: Int J Legal Med. 2003 Apr;117(2):106-8. Epub 2003 Feb 15.

Assisted suicide bordering on active euthanasia.

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A 44-year-old woman was almost completely paralysed after a severe brainstem haemorrhage. Even after several years of efforts at rehabilitation, she remained completely dependent on the help of others. However, a special device enabled her to administer (after careful preparation) liquids through the PEG catheter despite her poorly coordinated movements. Four years after the stroke, the woman joined a right-to-die society with the wish to bring her life to an end. A doctor working with this organisation prescribed her a lethal dose of pentobarbital. In the presence of her husband and her companion from the organisation, the woman administered herself the lethal substance by means of the device. On the basis of the fact that she herself had switched the device on this death was classed as (assisted) suicide.

PMID: 12690508 [PubMed - indexed for MEDLINE]

35: Int J Palliat Nurs. 2003 Jun;9(6):240-4.

Application of the doctrine of double effect in end stage disease.

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The aim of this article is to explore the doctrine of double effect and to identify whether it is appropriate to use the doctrine, and if so when, in end stage disease. The legal principles of the doctrine of double effect will be explored through the examination of three recent cases involving the death of a patient in the UK. The legal distinction between the doctrine of double effect and the intentional act of homicide will be discussed.

Publication Types:
Legal Cases

PMID: 12897695 [PubMed - indexed for MEDLINE]

36: Intern Med J. 2003 May-Jun;33(5-6):257-9.

Questioning the decision-making capacity of surrogates.

Library Program Office
Office of Information
Veterans Health Administration

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When patients are unable to make medical decisions for themselves due to cognitive impairment, surrogate decision makers are often called on to guide the medical team. Important to any decision made on behalf of the patient is that the decision reflects the values and preferences of the patient in light of the patient's clinical status and prognosis. Challenges arise for the medical team when surrogates themselves have questionable decision-making capacity due to psychosocial issues, conflict of interest, or the obvious projection of their own personal values and treatment preferences instead of the patient's. Even if an alternative surrogate is available, there is no consensus on when and how to switch from the primary surrogate to the alternative surrogate. This paper uses a clinical case to explore the notion of surrogate decision-making capacity, offering guidance for determining when it is appropriate to defer to an alternative surrogate, as well as guidance for managing the process of appointing the alternative as the new primary decision maker.

PMID: 12752897 [PubMed - indexed for MEDLINE]

37: J Am Coll Surg. 2003 Aug;197(2):323-30.

Legal considerations for palliative care in surgical practice.

Baluss ME, Lee KF.

The Pain Law Initiative, Washington, DC, USA.

Publication Types:

Review

Review, Tutorial

PMID: 12892818 [PubMed - indexed for MEDLINE]

38: J Am Geriatr Soc. 2003 Aug;51(8):1155-8.

Using the family covenant in planning end-of-life care: obligations and promises of patients, families, and physicians.

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Physicians and families need to interact more meaningfully to clarify the values and preferences at stake in advance care planning. The current use of advance directives fails to respect patient autonomy. This paper proposes using the family covenant as a preventive ethics process designed to improve end-of-life

planning by incorporating other family members--as agreed to by the patient and those family members--into the medical care dialogue. The family covenant formulates advance directives in conversation with family members and with the assistance of a physician, thereby making advance directives more acceptable to the family, and more intelligible to other physicians. It adds the moral force of a promise to the obligation of respecting a patient's preferences about end-of-life care. These negotiations between patient, family, and physician, from early planning phases through implementation, should greatly reduce the incidence of family disagreements on what the patient would have wanted. The family covenant ensures advance directive discussions within the family, promotes and respects the autonomy of other family members, and might even spur others in the family to complete advance directives through additional covenants. The family covenant holds the potential to transform moral quagmires into meaningful moral conversation.

PMID: 12890082 [PubMed - indexed for MEDLINE]

39: J Am Geriatr Soc. 2003 Aug;51(8):1149-54.

Ethical issues in end-of-life geriatric care: the approach of three monotheistic religions-Judaism, Catholicism, and Islam.

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Ethical dilemmas pervade modern geriatric medicine. What is considered right or wrong will differ depending on, among other things, the patient's religion. The three Abrahamic monotheistic religions, Judaism, Christianity (its Catholic variant), and Islam all have carefully considered positions on medical ethics. Although much is held in common, there are significant differences. The authors present three clinical cases, each of which presents ethical dilemmas typical of geriatric care, especially at the end of life. On the basis of these scenarios, the normative ethical position of each religion is compared and contrasted. It is hoped that this approach will offer the geriatrician a useful approach to treating patients in an increasingly multicultural society.

PMID: 12890081 [PubMed - indexed for MEDLINE]

40: J Fam Issues. 1999 Mar;20(2):269-89.

Family members' experiences with do-not-resuscitate (DNR).

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University of Nebraska Medical Center, USA.

PMID: 14509298 [PubMed - indexed for MEDLINE]

41: J Formos Med Assoc. 2003 Feb;102(2):97-104.

Psychometric testing of the translated McGill Quality of Life Questionnaire-Taiwan version in patients with terminal cancer.

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BACKGROUND AND PURPOSE: Quality of life (QOL) is the paramount goal of end-of-life care. However, there is no Chinese language instrument for measuring QOL that has been shown to have adequate psychometric properties for Taiwanese patients with terminal cancer. The purpose of this study was to examine the psychometric properties of a Chinese language version of the McGill Quality of Life questionnaire (MQOL-Taiwan version) in this population. **METHODS:** The original English version of the MQOL questionnaire was translated into Chinese, and administered to 64 Taiwanese patients with terminal cancer for psychometric testing (factor structures and various types of reliability and validity). The cultural equivalence of the translation was tested by content validity index. Statistical analysis included exploratory factor analysis, Pearson's product moment correlation coefficient, and the calculation of Cronbach's alpha (alpha). **RESULTS:** Findings on the validity and reliability of the MQOL-Taiwan version were as follows. The value of content validity was 0.98. The range of the correlations between an item and its domain was 0.59 to 0.96 (all $p < 0.05$), and for inter-domain was 0.28 to 0.52 (all $p < 0.05$). The 4 domains of the original MQOL emerged as the 4 dominant factors (64% total variance explained) in the MQOL-Taiwan version, namely the domains of physical symptoms, psychological symptoms, existential well-being, and support. The internal consistency (Cronbach's alpha) coefficient of the whole MQOL-Taiwan version was 0.83, and those for the 4 domains ranged from 0.69 to 0.90. For the convergent and divergent validity, the MQOL-Taiwan version physical domain was moderately and significantly ($r = -0.44$, $p < 0.05$) correlated with the performance status rating of the Eastern Cooperative Oncology Group-Performance Status Rating (ECOG-PSR). The MQOL-Taiwan version psychological, existential, and support domains were not significantly correlated to the ECOG-PSR. **CONCLUSIONS:** The MQOL-Taiwan version demonstrated an acceptable level of reliability, validity and equivalency in the initial cross-cultural validation. These findings indicate the suitability of this QOL measure for clinical and research use in Taiwanese patients with terminal cancer.

PMID: 12709738 [PubMed - indexed for MEDLINE]

42: J Med Philos. 2003 Apr;28(2):221-38.

Human health and stoic moral norms.

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For the philosophy of medicine, there are two things of interest about the stoic account of moral norms, quite apart from whether the rest of stoic ethical theory is compelling. One is the stoic version of naturalism: its account of practical reasoning, its solution to the is/ought problem, and its contention that norms for creating, sustaining, or restoring human health are tantamount to moral norms. The other is the stoic account of human agency: its description of the intimate connections between human health, rational agency, and moral norms. There is practical guidance to be gained from exploring those connections, whether or not one is ready to follow stoic moral theory all the way to its austere end.

PMID: 12943215 [PubMed - indexed for MEDLINE]

43: J Pain Symptom Manage. 2003 Aug;26(2):723-30.

Use of oral and transdermal opioids among patients with metastatic cancer during the last year of life.

Berger A, Dukes E, Smith M, Hagiwara M, Seifeldin R, Oster G.

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This study documents the use of oral and transdermal opioids among patients with metastatic cancer during their final year of life. Using a large, integrated health-insurance claims database, we identified all patients who had metastatic lung, breast, colorectal, prostate, or breast cancer and who also died in 1998 or 1999. We then examined all pharmacy claims for these patients over their final 12 months of life. A total of 2,132 patients were identified who met study entrance criteria. Among patients with bone metastases (n=717), 86.9% received opioids at some point during their final year of life; 71.2% of those without bone metastases (n=1,415) received them. Corresponding figures for long-acting opioids were 52.9% and 23.5%. Coverage ratios (total days supplied/total noninstitutionalized days) for any opioids and long-acting opioids were 25.1% and 12.5%, respectively, among patients with bone metastases, and 13.9% and 4.2% for those without bone metastases. During the final month of life, these ratios were 50.8% and 31.3%, and 28.7% and 13.1%. These relatively low rates of opioid use among patients with metastatic cancer in their final year of life suggest that pain in many cases may be suboptimally treated.

PMID: 12906957 [PubMed - indexed for MEDLINE]

44: J Pain Symptom Manage. 2003 Aug;26(2):693-5.

Poor social conditions, criminality and urban violence: Unmentioned barriers for effective cancer pain control at the end of life.

Soares LG.

Publication Types:
Letter

PMID: 12906953 [PubMed - indexed for MEDLINE]

45: J Palliat Med. 2003 Aug;6(4):575-84.

Validation of a new measure of concept of a good death.

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BACKGROUND: The concept of a good death is central to end-of-life care research. Despite its importance and the high interest in the topic, there are few measures currently available for use in clinical research. **PURPOSE:** The present work describes the development and testing of a set of items intended to measure the importance of several components posited to be critical to the concept of a good death. It is intended for use with health care providers and lay people in the context of end-of-life care research and education. **POPULATION:** Four cohorts (n = 596) were recruited to participate, representing two helping profession disciplines, nonhelping professionals, and a range of ages, specifically: (1) undergraduate medical students; (2) master's degree students in nursing; (3) graduate students from the life sciences; and (4) practicing hospice nurses. **METHODS:** Participants completed self-report questionnaires at baseline and retest. Psychometric analyses included item frequency distributions, factor analysis, alpha reliability, intraclass correlation, and measures of association. **RESULTS:** The new Concept of a Good Death measure demonstrated good item frequency distributions, acceptable internal consistency reliability, and test-retest stability. Its factor structure revealed that three distinct domains are measured, reflecting the psychosocial/spiritual, physical, and clinical aspects of a good death. An examination of patterns of correlations showed differential associations with death anxiety, spiritual beliefs and practices, anxious mood, and sociodemographic characteristics. **CONCLUSIONS:** The new Concept of a Good Death instrument appears to measure three distinct factors which people consider important to a Good Death. Ratings of the importance of these factors are reliable and valid. The instrument has the advantage of being a brief, self-report index for use in end-of-life care research.

PMID: 14516499 [PubMed - in process]

46: J Palliat Med. 2003 Aug;6(4):605-13.

Competency in end-of-life care: last hours of life.

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Clinical competence, willingness to educate, and calm and empathic reassurance are critical to helping patients and families in the last hours of living. This review adapted from the Education for Physicians on End-of-Life Care (EPEC) Curriculum describes the predictable course that occurs as well as approaches to management. Management principles are the same at home or in a health care institution. However, death in an institution requires accommodations to assure privacy, cultural observances, and communication that may not be customary. In anticipation of the event, it helps to inform the family and other professionals about what to do and what to expect. Care does not end until the family has been supported with their grief reactions and those with complicated grief helped to get care. Care at the end of life is a core competency.

PMID: 14516502 [PubMed - in process]

47: J Palliat Med. 2003 Aug;6(4):661-9.

"Do It Your Way": a demonstration project on end-of-life care for persons with serious mental illness.

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Over the last decade, America's health care systems have been challenged to incorporate advance care planning and end-of-life care into their service delivery systems to assure that persons with terminal illnesses receive compassionate individualized care. Despite the surge in new research and knowledge, some groups remain understudied and underserved, such as persons with serious mental illness. "Do It Your Way," a demonstration project, was developed and implemented in a Massachusetts public mental health system to improve access to advance care planning and end-of-life care among persons with serious mental illness. This report provides an overview of the project, including its rationale, setting, needs assessment, objectives, initiatives, preliminary evaluation, impact, and conclusions.

PMID: 14516513 [PubMed - in process]

48: J Palliat Med. 2003 Aug;6(4):671-83.

CHOICES: promoting early access to end-of-life care through home-based transition management.

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CHOICES is a comprehensive home-based care coordination program designed to

bridge the gap between home health and hospice for Medicare + Choice enrollees with advanced chronic illness in San Francisco's East Bay region. Key elements of the program include physician education, enrollment of patients with high disease burden who may not be terminally ill, co-management of care with the primary physician, and an advanced practice clinical team that provides comprehensive in-home assessments, a flexible mix of life-prolonging and palliative care that evolves with disease progression, focused education and advance planning, and caregiver support. During a 42-month demonstration, 208 patients were enrolled in the program. Eighty percent had a non-cancer diagnosis; 40% were people of color. After an 8-month follow-up, 44% of the study cohort had died in the program or after transfer to hospice, 51% had been discharged, and 5% remained active. Median length of stay for decedents was 260 days. Preliminary evidence supports the program's feasibility and acceptability to patients, families, physicians, and agency partners. However, the uncertain future of Medicare + Choice and of managed care may jeopardize the program's sustainability. Policymakers and taxpayers will need to determine how to care for the growing number of chronically ill elderly who wish to remain at home as illness advances. The care needs of these patients and their families may overwhelm a health system organized around hospital treatment of acute illness.

PMID: 14516514 [PubMed - in process]

49: J Palliat Med. 2003 Aug;6(4):543-56.

A palliative care needs assessment of health care institutions in Wisconsin.

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BACKGROUND: In 1999 the Wisconsin Coalition to Improve Palliative Care (WCIPC) conducted a palliative care needs assessment of health care institutions throughout the state of Wisconsin to document the current status of palliative care and identify institutional barriers and opportunities for improvement. **METHOD:** A survey instrument was developed to assess provisions of palliative care in the following areas: services currently provided, staff education programs offered in the previous year, barriers to the delivery of palliative care, and resources that would be useful to the participating institutions. Surveys were mailed to 881 health care institutions in Wisconsin; 318 (36%) surveys were returned. **RESULTS:** The three most common end-of-life care services present included a program to promote advance care planning, a contractual relationship with one or more hospice programs, and an interdisciplinary care program for dying patients. Pain management and advance directives were the two most common topics of educational programs offered in the past year. The most frequently cited barriers to good end-of-life care included a lack of knowledge among patients/families, a lack of provider knowledge about pain and symptom control, and poor reimbursement for end-of-life care. Resources that institutions felt would be useful included newsletters, a speaker's bureau, and information about establishing quality improvement programs for palliative care. **CONCLUSIONS:** While health care institutions in Wisconsin provide a variety of palliative care services and offer educational programs that address areas of

palliative care, institutional barriers do exist. This needs assessment provides valuable descriptive data that will guide efforts to improve palliative care throughout the state of Wisconsin.

PMID: 14516496 [PubMed - in process]

50: J Palliat Med. 2003 Jun;6(3):391-9.

Palliative care education: an intervention to improve medical residents' knowledge and attitudes.

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BACKGROUND: Medical care at the end of life remains poor. One approach to improving end-of-life care is through education of medical trainees. However, evidence regarding the structure of an ideal educational intervention is sparse. **OBJECTIVE:** To test an innovative curriculum designed to improve medical resident knowledge and decrease anxiety surrounding end-of-life care. **METHODS:** Quasiexperimental study of medical trainees in a large academic internal medicine residency. Attitudes and knowledge were measured at baseline and at completion of a 1-month clinical ward rotation for both control ($n = 40$) and intervention groups ($n = 30$) using the Collett-Lester Death Anxiety Scale (C-LDAS), the Semantic Differential Scale (SDS), and a 16-question knowledge-based test. Residents in the intervention group completed four 1-hour sessions focused on end-of-life issues. **RESULTS:** Baseline anxiety levels were high while knowledge scores were poor. Linear regression modeling demonstrated that pretest scores were the strongest predictor of post-test scores for all three measures. Additional significant predictors for the knowledge test were prior palliative care experience and year of training ($p = 0.02$), while prior palliative care experience alone contributed to the SDS model ($p = 0.06$). No significant improvements on the SDS, C-LDAS, or knowledge test occurred after the curriculum intervention. **CONCLUSIONS:** Our classroom intervention had no significant effect on residents' attitudes towards or knowledge of end-of-life care. The fact that prior palliative care experience affects baseline scores provides a strong argument for continued research for an effective curriculum for end-of-life education, perhaps focusing on clinical rather than didactic experiences in palliative care.

PMID: 14509484 [PubMed - in process]

51: J Palliat Med. 2003 Jun;6(3):511-9.

Enhancing communication for end-of-life care: an electronic advance directive process.

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An advance directive, a description of one's future preferences for medical treatment, must be easily available to care providers to ensure that one's treatment preferences are honored. The transition of our health care system to an electronic medical record complicated the availability of a patient's written advance directive. This paper describes the development of an electronic advance directive to facilitate access to a patient's treatment wishes at any site in our health care system. The successes and challenges encountered in the development process are discussed.

PMID: 14509500 [PubMed - in process]

52: J Palliat Med. 2003 Jun;6(3):501-10.

Establishing a culturally sensitive palliative care program in rural Alaska Native American communities.

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End-of-life programs that provide an option for patients to die at home are available in most U.S. communities. However, Alaska Natives living in remote Alaska villages often die alone in hospitals and nursing homes hundreds of miles away from home. The Bristol Bay Area Health Corporation (BBAHC), a tribal organization, is the sole provider of comprehensive primary care services to 34 Alaska Native villages located within a 46,000 square mile area in southwest Alaska. The closest tertiary care hospital is 329 air miles away in Anchorage. Because of the high cost of, and difficulties encountered in trying to deliver end-of-life care services to remote communities, a village-focused, culturally sensitive, volunteer and primary care program combined with a regionally based physician and home health nurse to deliver multi-disciplinary palliative care was developed. The Helping Hands Program blends cultural practices with contemporary palliative care medicine to allow Alaska Natives and others living in remote communities to be cared for at home through the end of life. Since the program was implemented in 1999, the percentage of home deaths for selected causes has changed from 33% in 1997 to 77% in 2001. The Anchorage-based Alaska Native Tribal Health Consortium (ANTHC) and the Alaska Native Medical Center (ANMC) have recognized the importance and success of the BBAHC program and are investigating expanding the program to other parts of Alaska. Centralizing the program in Anchorage will allow staff trained in palliative care to travel to regional Alaska Native hospitals to help train health care professionals.

PMID: 14509499 [PubMed - in process]

53: J Psychosoc Nurs Ment Health Serv. 2003 Aug;41(8):28-36.

Use of a values history in approaching medical advance directives with psychiatric patients.

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The Patient Self-Determination Act became federal law in 1990. However, many psychiatric facilities are just beginning to actively address the issue of medical advance directives. The term advance directives, for the purposes of this article, refers exclusively to medical advance directives. Psychiatric advance directives, which are related to issues such as involuntary hospitalization, are beyond the scope of this article.

PMID: 13677009 [PubMed - indexed for MEDLINE]

54: J R Soc Med. 2003 Aug;96(8):411.

A new kind of living will.

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PMID: 12893865 [PubMed - indexed for MEDLINE]

55: JAMA. 2003 Sep 24;290(12):1578; author reply 1578-9.

Comment on:
JAMA. 2003 May 7;289(17):2238-45.

Hospice use in Medicare beneficiaries with cancer.

Gagnon B.

Publication Types:
Comment
Letter

PMID: 14506113 [PubMed - indexed for MEDLINE]

56: Minerva Anesthesiol. 2003 Apr;69(4):180-3.

Clinical decision making during resuscitation and guidelines for termination of the resuscitation effort.

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Cardiopulmonary resuscitation (CPR) is the appropriate intervention to sustain respiratory and circulatory functions in patients with diseases that are potentially reversible; while CPR is unequivocally inappropriate for patients with terminal diseases when there is a consensus of medical opinion that is no reasonable likelihood of meaningful survival. In practical application patients and their families seek guidance based on understanding. CPR when employed without expectations of benefit, will be likely to further compromise neurological function, produce iatrogenic injury, and add discomfort to the dying patient. The decision not to resuscitate remains a reasoned medical judgement. In some condition, transferring the patient with terminal diseases to an alternate physician or institution is ultimately respectful both for the patient and of physician.

PMID: 12766704 [PubMed - indexed for MEDLINE]

57: N Engl J Med. 2003 Sep 18;349(12):1123-32.

Comment in:

N Engl J Med. 2003 Sep 18;349(12):1109-10.

Withdrawal of mechanical ventilation in anticipation of death in the intensive care unit.

Cook D, Rucker G, Marshall J, Sjökvist P, Dodek P, Griffith L, Freitag A, Varon J, Bradley C, Levy M, Finfer S, Hamielec C, McMullin J, Weaver B, Walter S, Guyatt G; Level of Care Study Investigators and the Canadian Critical Care Trials Group.

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BACKGROUND: In critically ill patients who are receiving mechanical ventilation, the factors associated with physicians' decisions to withdraw ventilation in anticipation of death are unclear. The objective of this study was to examine the clinical determinants that were associated with the withdrawal of mechanical ventilation. **METHODS:** We studied adults who were receiving mechanical ventilation in 15 intensive care units, recording base-line physiological characteristics, daily Multiple Organ Dysfunction Scores, the patient's decision-making ability, the type of life support administered, the use of do-not-resuscitate orders, the physician's prediction of the patient's status, and the physician's perceptions of the patient's preferences about the use of life support. We examined the relation between these factors and withdrawal of mechanical ventilation, using Cox proportional-hazards regression analysis. **RESULTS:** Of 851 patients who were receiving mechanical ventilation, 539 (63.3 percent) were successfully weaned, 146 (17.2 percent) died while receiving mechanical ventilation, and 166 (19.5 percent) had mechanical ventilation withdrawn. The need for inotropes or vasopressors was associated with withdrawal of the ventilator (hazard ratio, 1.78; 95 percent confidence interval, 1.20 to 2.66; $P=0.004$), as were the physician's prediction that the patient's likelihood of survival in the intensive care unit was less than 10 percent (hazard ratio, 3.49; 95 percent confidence interval, 1.39 to 8.79; $P=0.002$), the physician's

prediction that future cognitive function would be severely impaired (hazard ratio, 2.51; 95 percent confidence interval, 1.28 to 4.94; P=0.04), and the physician's perception that the patient did not want life support used (hazard ratio, 4.19; 95 percent confidence interval, 2.57 to 6.81; P<0.001).

CONCLUSIONS: Rather than age or the severity of the illness and organ dysfunction, the strongest determinants of the withdrawal of ventilation in critically ill patients were the physician's perception that the patient preferred not to use life support, the physician's predictions of a low likelihood of survival in the intensive care unit and a high likelihood of poor cognitive function, and the use of inotropes or vasopressors. Copyright 2003 Massachusetts Medical Society

PMID: 13679526 [PubMed - indexed for MEDLINE]

58: N Engl J Med. 2003 Sep 4;349(10):1002-4; author reply 1002-4.

Comment on:

N Engl J Med. 2003 May 15;348(20):2007-18.

Heart failure.

Schoevaerdts D, Swine C, Vanpee D.

Publication Types:

Comment

Letter

PMID: 12959102 [PubMed - indexed for MEDLINE]

59: Nephrol News Issues. 2003 Jul;17(8):28-31.

Palliative care in chronic kidney disease: peer mentoring program personalizes advance directives discussions.

Perry E, Swartz J, Kelly G, Brown SL, Swartz RD.

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Medical professionals in nephrology are trained to think about improving quality and quantity of life with their patients, but only recently are they being urged to consider ways to improve end-of-life care. For many staff, this still feels contradictory. One nephrologist recently told these authors, "I was trained to help people live, not to help them die." The RWJF Promoting Excellence in End-of-Life Care work group has investigated, accumulated, and designed resources to help renal teams improve in this challenging arena. Peer mentoring is one such powerful resource, and, once in operation, is cost free. In conjunction with renal social work and the renal team, peer mentoring is a wonderful program that can decrease anxiety and preserve caring relationships in our burgeoning dialysis communities.

Publication Types:

Review
Review, Tutorial

PMID: 12882109 [PubMed - indexed for MEDLINE]

60: Nephrol News Issues. 2003 Jul;17(8):32-4.

From here to eternity. How do physicians learn to let go? Part 1.

Bartlow B.

In the next installment of this series, I'll suggest how we might proceed once we've acknowledged that death may be the next appropriate treatment. Did God just invent death and dying on a bad hair day--kind of a final "Take that!"? Or, is the last of life as rich in promise and purpose as the birth with which it began?

PMID: 12882110 [PubMed - indexed for MEDLINE]

61: Nurs Educ Perspect. 2003 Jul-Aug;24(4):184-5.

Incorporating concepts of end-of-life care into a psychiatric nursing course.

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Providing quality care to patients who are at the end of life is recognized as an important aspect of health care. Nurse educators are in a unique position to influence future care by imparting essential information on this topic to students during their basic nursing education. The author offers support for the suggestion that select end-of-life concepts be included in psychiatric-mental health nursing courses and presents suggestions for incorporating such concepts into psychiatric nursing clinical learning experiences.

PMID: 14528863 [PubMed - in process]

62: Nurs Educ Perspect. 2003 Jul-Aug;24(4):176-83.

Communication skills for end-of-life nursing care. Teaching strategies from the ELNEC curriculum.

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The End of Life Nursing Education Consortium (ELNEC) is a train-the-trainer educational program that helps nursing faculty integrate care of the dying patient and the patient's family into the nursing curriculum. This article

presents pedagogical techniques derived from the ELNEC teaching module on communication and key content areas for developing communication skills in end-of-life care. Competent end-of-life nursing care begins with an understanding of communication techniques and their potential impact on care.

PMID: 14528862 [PubMed - in process]

63: Nurs Ethics. 2003 Jul;10(4):377-87.

Nurses and the virtues of dealing with existential questions in terminal palliative care.

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We have conducted a small qualitative empirical study into the problems that nurses encounter in delivering existential support in their care of dying patients. We found that nurses are confronted with four types of problem: determining whether the patient actually has put a genuine question for existential support on the agenda; assessing what the import of such a question is; devising an adequate procedure for offering existential support; and organizing adequate support for themselves. Our analysis shows that it takes a 'fine-tuned antenna' from nurses to determine these existential questions, which are often put indirectly and in a variety of forms. We have attempted to show that the subtleties of the communicative dimension of palliative terminal care require an intricate set of virtues on the part of the nurse. We have analysed these virtues in a bottom-up approach, inferring them directly from the material obtained from interviews. The framework utilized is the Aristotelian one of striking the right balance between the poles of a morally relevant dimension.

PMID: 12875535 [PubMed - indexed for MEDLINE]

64: Nurse Educ. 2003 Jul-Aug;28(4):149-50.

Encouraging student nurses' creative expression about end-of-life experiences.

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PMID: 12878889 [PubMed - indexed for MEDLINE]

65: Pain Med. 2003 Jun;4(2):125-34.

The terminal cancer patient: effects of age, gender, and primary tumor site on opioid dose.

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OBJECTIVE: The objective of the current study is to describe correlations between age, gender, and primary cancer site and sustained-release opioid doses prescribed for hospice patients at the end of life. **PATIENTS AND SETTING:** This study included all 7,201 hospice patients referred to a North American palliative care specialty pharmacy with the primary diagnosis of cancer and who were prescribed transdermal fentanyl, sustained-release oral morphine, or sustained-release oxycodone. **DESIGN:** This is a retrospective analysis of the final sustained-release morphine, oxycodone, or transdermal fentanyl doses prescribed to cancer patients, according to pharmacy records. Comparisons between sex and age group were performed with chi-square tests. Mann-Whitney U tests were used to compare mean doses between the sexes. Analyses of covariance (ANCOVA) were used to compare opioid doses between genders and among primary cancer sites while controlling for age. **RESULTS:** The inverse association between age group and dose was highly significant. For example, final opioid doses ≤ 120 mg/day oral morphine equivalent were prescribed for only 46.4% of patients between 40 and 49 years of age compared with 86.4% of patients 90 years of age and older. An ANCOVA on the largest non-sex-related diagnoses found primary tumor site and patient age, but not gender, to be associated with sustained-release opioid dose. **CONCLUSIONS:** Both primary tumor site and patient age were associated with final opioid dose. Further investigation is warranted to determine which primary tumor sites are associated with unusually high opioid doses and may highlight the need to optimize adjuvant medication therapy if neuropathic and/or inflammatory pain mechanisms are involved and to refer to pain specialists when appropriate.

PMID: 12873262 [PubMed - indexed for MEDLINE]

66: Pain Med. 2003 Mar;4(1):81-4.

Pain management at the end of life: often a difficult call.

Dubois MY, Fine PG, Fischberg D, Ferrell B, Taylor ML.

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PMID: 12873281 [PubMed - indexed for MEDLINE]

67: Palliat Med. 2003 Jun;17(4):375-7.

Brief report on user involvement at St Christopher's Hospice.

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As part of their Clinical Governance agenda, St Christopher's Hospice in

southeast London has established a system for gaining patient and carers' views, in order to ensure these are given adequate consideration in planning and providing services. A users forum has been set up, and this article discusses some of the issues that had to be addressed in organizing the forum. Items such as who to invite, who should facilitate the meetings, venue, timetable, and boundaries all needed to be agreed. Evaluation of the usefulness of the forum is still required, with many questions still to be answered, but so far staff, patients and carers have enthusiastically embraced the forum. This report identifies some of the challenges in developing a person-centred user involvement scheme in a voluntary hospice.

PMID: 12822855 [PubMed - indexed for MEDLINE]

68: Scand J Caring Sci. 2003 Jun;17(2):113-21.

Vulnerability of family caregivers in terminal palliative care at home; balancing between burden and capacity.

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This paper reports on a grounded theory interview-based study with 13 family members aged 28-80 years caring for terminally ill people at home (with a life expectancy of 3 months or less) in the Netherlands. The project was approved by the ethics committee of the Maastricht University Hospital. The aim of this study was to explore the experiences of family caregivers, their needs for home care, and which health services they receive. Data were analysed using the constant comparative method. 'Vulnerability' was identified as the core category. Caring for a terminally ill person at home requires continuous balancing between care burden and capacity to cope. Whether or not the carer will succeed in keeping in optimum balance is dependent on a number of factors impinging on the caregiver's vulnerability. Care burden, restricted activities, fear, insecurity, loneliness, facing death, lack of emotional, practical and information-related support were identified from the data as factors having the potential to increase the caregiver's vulnerability, and may be risk factors for fatigue and burnout. Continuing previous activities, hope, keeping control, satisfaction and good support are factors which may decrease the caregiver's vulnerability, and may protect against fatigue and burnout. The experiences of the caregivers in our study showed that the support from informal and professional caregivers was not sufficient. Education and practical tools may make professionals more sensitive for the vulnerable position of family caregivers, even when these caregivers do not show their vulnerability.

PMID: 12753511 [PubMed - indexed for MEDLINE]

69: Soc Sci Med. 2003 Oct;57(8):1375-85.

Disarmed complaints: unpacking satisfaction with end-of-life care.

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Difficult health care encounters often do not translate into expressions of dissatisfaction with care. This paper focuses on the 'non-expression' of dissatisfaction with care in the accounts of 12 people in Canada who provided care to a relative or friend who died of breast cancer. The analysis foregrounded in this paper began from the observation that as difficult health care experiences were elaborated, speakers located health professionals' actions in relation to various situational factors, including the fact of a (cancer) death and conditions of constraint in the health system. Set alongside these two realities, expressions of dissatisfaction tended to be disarmed. Results of this study suggest that the cost of articulating dissatisfaction with care is high where the cared-for person has died, and the perceived value of focusing on difficult experiences is low. Further, respondents in this study took the specificity of the situation and the setting into account in formulating beliefs about the care outcomes for which health professionals could be held responsible. When conditions in the health system and the disease process of advanced cancer were positioned in talk as 'ultimate limits' on health professionals' actions, perceived lapses in care were excused.

PMID: 12927468 [PubMed - indexed for MEDLINE]

70: Soc Work Health Care. 2003;37(2):43-70.

Washington State social workers' attitudes toward voluntary euthanasia and assisted suicide.

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This study examines attitudes and experiences concerning voluntary euthanasia (VE) and assisted suicide (AS) among 862 professional social workers from Washington State, USA. Although AS has been portrayed as more acceptable than VE, social workers make only a minor distinction in their support for the legalization of such acts (VE 72.4%; AS 77.6%). Only 26.6% agreed with the US Supreme Court's ruling that assisted suicide is not a constitutional right. More than 75% believe that social workers should be involved in the decision-making process with clients who are considering VE/AS. About 20% of social workers report being consulted about VE/AS issues either by clients or in their personal lives. Social workers employed in medical settings are more than twice as likely to be consulted about VE/AS than those employed in non-medical settings. Religious commitment explains some opposition to VE/AS for Protestants and Catholics, but not for other faiths. A small number of social workers (19) admitted to assisting the death of a patient by VE and 5 admitted to AS.

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71: Soc Work Health Care. 2003;37(2):1-16.

Surrogate decision-making: judgment standard preferences of older adults.

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This qualitative study examines the judgment standard preferences of older adults related to surrogate decision-making for medical treatment. Thirty community dwelling adults over the age of 60 were presented with scenarios that depicted three decision-making standards, two of which are the predominant legal standards (substituted judgment and best interests), and a proposed third standard that allows the surrogate to consider the interests of the family in the decision-making process (best judgment). Half of the sample preferred substituted judgment, five preferred best interests, and ten chose best judgment. Selected cases are presented that demonstrate the themes associated with each judgment standard preference.

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